

UsAgainstAlzheimer's Survey #6 on COVID-19 and Alzheimer's Community Summary of Findings, September 2020

UsAgainstAlzheimer's fielded its sixth survey on the effects of the coronavirus on people affected by Alzheimer's disease and other dementias from September 3-9, 2020. The survey continued to assess levels of caregiver stress, effects on care and behaviors of people living with the disease, and restrictions on visitation in long-term care communities. This survey also had questions on attitudes about a potential COVID-19 vaccine and voting safety.

Nearly a Third of Caregivers and Overall Respondents Unsure about COVID-19 Vaccine

- 58% of current caregivers (and 60% of the overall cohort of respondents) intended to get a COVID-19 vaccine, once one is available. However, **30% of caregivers (31% of overall cohort) said they were unsure about whether they will get a vaccine.**
- In contrast, 86% of current caregivers (87% of overall cohort) intended to get a flu shot this season. Only 4% of each group said they were unsure about getting a flu shot.
- 69% of caregivers with loved ones in a long-term care community said they intended to request a COVID-19 vaccine for their loved one, once a vaccine is available, but wanted robust safety and efficacy data. In addition, 90% of these caregivers intended to request a flu shot for their loved one in a long-term care community.

Six in 10 Intended to Vote Absentee in the Presidential Election due to Virus Concerns

- Nearly all (96% of current caregivers and of overall respondents) intended to vote in this year's Presidential election.
- The majority of caregivers (61%) and overall respondents (58%) **planned to vote by absentee ballot**, with 8% of caregivers—and 10% of overall respondents—unsure.
- 55% of current caregivers (and overall respondents) were uncomfortable about voting in-person in light of the potential to be exposed to the coronavirus. About a third (31%) said they were comfortable voting in-person.
- 45% of current caregivers (and 50% of overall respondents) received information on how to vote safely.

Memory and Behavior Declines Seen for those with Dementia during Closures/Isolation

- Since coronavirus restrictions, closures and isolation have been in place, two-thirds (67%) of caregivers observed a **decline in their loved ones' memory or behaviors**. This includes 23% who reported a significant decline. Another 30% of caregivers said there had been no change in the memory or behaviors in their loved one.
- Of the 50 patient respondents—those diagnosed with mild cognitive impairment, Alzheimer's or another dementia—44% said they believed their cognition had declined somewhat, another 2% said they had experienced significant declines, and 54% said there had been no change.

Significant Stress and Effects on Current Caregivers (189 respondents)

- 78% percent of caregivers said their **stress** level was higher since coronavirus restrictions were put in place.
- 78% of caregivers reported having one or more **stress symptoms typically found in people experiencing severe stress**.

- Top-reported caregiver symptoms associated with stress among the total group remained largely unchanged. (Respondents could select more than one choice, and percentage is of total caregivers.) **Top stressors** included:
 - Loss of interest in activities (36%)
 - Vigilance/being 'super alert' (34%)
 - Sleep problems (33%)
 - Trouble experiencing positive feelings (29%)
 - Difficulty concentrating (24%)
 - Irritable/angry behavior (21%)
- More than a quarter (27%) of caregivers said physical or mental health changes related to the coronavirus pandemic and isolation affected their **ability to care for their loved one**.
- 30% of caregivers said they needed and could not get access to **support groups**; 24% needed and could not get access to **home health aides**.
- 73% of caregivers felt **more isolated** than before coronavirus restrictions.
- 52% of caregivers were more concerned about their **financial health** and their family's finances than before the coronavirus.
- 33% said that sheltering-in-place for their family was creating **additional tension about keeping their loved one at home**. 34% said it was hard for them or another family member to be close to a loved one with Alzheimer's 24 hours a day.
- 35% of caregivers noted they had less family support for caregiving as a result of coronavirus restrictions.

Continued Uncertainty of Plans if Alzheimer's Caregiver Became Sick with COVID-19

- 63% of those taking care of people with Alzheimer's disease at home were unsure what would happen to their loved one if the caregiver got sick with COVID-19. This is lower than most previous surveys—which averaged above 70%.
- 23% of caregivers were unsure what to do if their loved one with Alzheimer's became sick.

Concerns about Care of Loved Ones in Assisted Living Facilities (29 respondents)

A set of 29 respondents who reported having loved ones with Alzheimer's or another dementia in assisted living facilities continued to have higher stress because of visitation restrictions and challenges getting information about their loved one. The July survey showed that more people were able to visit loved ones in a long-term care community. This September survey showed increasing numbers of COVID-19 tests, and more COVID-19 cases, in the care communities where loved ones lived.

- 62% were **unable to see their loved one** because of virus-related visitation restrictions, a decline of 6 points from the July survey, and 29 points from the June survey.
 - Those who visited their loved ones in assisted living facilities said they would agree to the following restrictions by the facilities: no touching loved one (64%), health self-evaluation (64%), temperature check (64%), outside-only visits (55%), restricted number of visits (45%).
 - Caregivers were willing to consider the following safeguards when visiting their loved one in a long-term care community: wearing personal protective equipment (93%), socially distanced visiting (85%), getting tested for COVID-19 before

visiting (67%), video visiting as an alternative to in-person visiting (41%), paying for COVID-19 testing before visiting (41%).

- 67% said they had heard of cases of COVID-19 in the assisted living facility at the time of this survey (September 3-9), up 9 points since the July survey, 17 points since the June survey, 36-points since the May survey, and 50 points higher than the April survey.
- Nearly three-quarters of caregivers (74%) said that their **loved one had been tested for COVID-19** (up 3 points from the July survey), 15% said their loved one had not been tested, and 11% didn't know.
- Over three-quarters (78%) noted that their stress level was worse (compared with before the pandemic) relating to care of their loved one in an assisted living facility.
- 97% supported **required COVID-19 testing** of all nursing home residents and staff, with the remainder unsure, or having no opinion.
- Top stressors of caregivers with loved ones in assisted living facilities included:
 - Inability to know/accurately **assess health status** (93%)
 - Concern about facility's ability to adequately care for their loved one (37%)
 - Communications from facility on status of resources and supplies (37%)
- 33% were **less confident about the level of care** for their loved one since the coronavirus restrictions were put into place.
- 17% were concerned enough that they considered moving them from assisted living.

Ongoing Unmet Needs of People Diagnosed with MCI, Alzheimer's or Another Dementia (50 respondents)

A set of 50 respondents, who identified themselves as having been diagnosed with mild cognitive impairment, Alzheimer's or another dementia, reported unmet needs during the restrictions.

- 36% of diagnosed individuals wanted and could not get services in light of coronavirus restrictions. These included counseling (8%), pastoral care/religious services (10%), assistance with food shopping (6%), and family support (8%).

Survey Methodology: The survey, taken September 3-9, 2020 by the UsAgainstAlzheimer's A-LIST®, had 905 responses overall from people living with Alzheimer's or another dementia, current and former caregivers, people with a significant likelihood of developing the disease, and those interested in brain health. Of the total respondents, 876 described their status. Current caregivers were the largest group, with 231 responses. Of the 189 caregivers completing the survey, a subset of 29 respondents said they had a loved one in an assisted living facility. In addition, 50 individuals with Alzheimer's disease or Mild Cognitive Impairment also took the survey. This research is overseen by an Institutional Review Board (IRB.)

The UsAgainstAlzheimer's COVID-19 survey series is supported in part by the Eisai USA Foundation, naviHealth and Biogen, with research support from Cohen Veterans Bioscience.